



SPINAL COURIER

SPINAL CORD
COMMISSION

Vol. 10, No. 1

October 1998

Arkansas Selected to Test Consumer-Directed Care: *IndependentChoices*

Arkansas is one of four states selected to receive a Robert Wood Johnson Foundation and U.S. Health and Human Services Cash and Counseling Grant. In Arkansas the project, which is called *IndependentChoices*, will be managed by the Arkansas Department of Human Services, Division of Aging and Adult Services.

IndependentChoices offers qualified participants the opportunity to direct their own personal care with a monthly cash allowance. The allowance will replace agency provided personal care. Participants may use the cash allowance to purchase items related to personal care or the money may be used to hire a personal care

assistant. The person they hire may be a friend, neighbor or relative (exception: a spouse may **not** be a paid assistant).

IndependentChoices is available to Medicaid recipients who are at least 18 years old and are receiving Medicaid Personal Care or are medically eligible for personal care and want to participate. The participant must be able to direct his/her own care with a monthly cash allowance. If unable to self-direct, a representative may serve as the decision-maker. The project offers participants support in managing the allowance with counseling services and the use of a fiscal agent or bookkeeper.

IndependentChoices is a research project that will shape home services in the future. To assure valid results, the project will compare the outcomes of two groups, one receiving the cash allowance and the other receiving agency provided services. Only half of the people who enroll will receive the cash allowance. The other half will continue to receive the agency services.

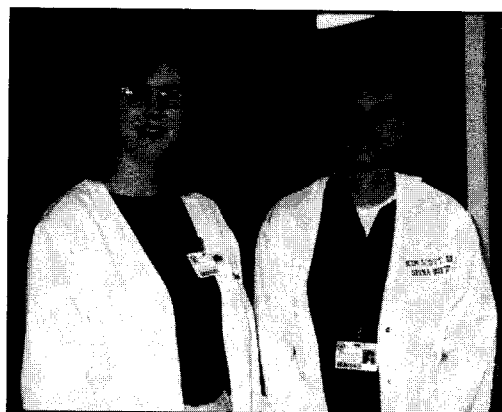
If you are interested in becoming part of the *IndependentChoices* project or know someone who might qualify, please call the *IndependentChoices* toll-free number, **1-800-682-0044**, to obtain additional information. &

New Faces, New Spaces at Spina Bifida Clinic !

As many of you are already aware, there have been many changes in the Spina Bifida Clinic (SBC) at Arkansas Children's Hospital (ACH) this year. The biggest change has been in the staff. In March, **Becky Watkins-Bregy**, RNC assumed the position of Program Coordinator. **Kim Scott**, RN came on as Clinical Care Coordinator in May. Both Kim and Becky are long time ACH employees and come to the clinic from the Turning Point program. **Bonnie Berryman** joined the staff as

office secretary in August; so if you call, you will most likely talk with her first.

Becky, Kim and Bonnie bring great enthusiasm and organization to the clinic. In addition, they are very involved in community outreach and were involved in Super Spokes this summer. Kim helped at Spina Bifida Camp, while Becky attended the national Spina Bifida Association meeting. One of their primary goals has been to decrease the "dinkas" (did not



New SBC staff members, Becky Bregy, RNC (left) and Kim Scott, RN (right).

keep appointment). To assure that needed clinic appointments are made and kept, Kim has been personally contacting families to set
Continued on pg. 3 - see "Spina Bifida Clinic"

SPINAL COURIER

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With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at (501) 296-1788 / 1-800-459-1517 / TDD (501) 296-1794 or send your donation to:

**AR Spinal Cord Commission
1501 North University, Suite 470
Little Rock, AR 72207**

Donations this quarter from:

Mike Long

*In memory of Linda McDougal
Linda Shearer*

*In memory of Helen Smith
Mr. and Mrs. John Allen*

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Vaccinations

Dear Editor:

I want to remind the readers of *Spinal Courier* to get their flu vaccination this year. The best time to get your annual flu injection is in October or November. At the same time I want you to think about getting or assessing if you need the following vaccinations:

- **Pneumococcal Vaccination** - the Centers for Disease Control recommends routine administration to persons over age 65, those with chronic respiratory disease and those who live in chronic-care facilities. If you

fall in one of these categories, I suggest you discuss getting the vaccination with your doctor. In most instances, it is only needed once in a life time, but there is some data to suggest that it may need to be repeated after ten years.

- **Tetanus-Diphtheria Toxoid** - a booster injection is needed every ten years. Tetanus is very uncommon in the U.S. but remains a serious infection (if contracted, death occurs in 26-31% of cases). Again, discuss with your doctor or go to your local health department.

*Tom Kiser, M.D.
ASCC Medical Director*

From the Director

Standing outside in 101 degree weather at Garland County Community College on a Saturday in July, I asked myself, "What am I doing out here?" Then I looked around me at the young wheelchair users there to participate in our Super Spokes program, their parents, brothers and sisters and all the other volunteers present — and I remembered why. We were there to assure that at least the 30 kids who participated that weekend got a chance to try some new sports, develop some new skills and maybe make a new friend or two along the way.

Junior Rollin' Razorback Coach Doug Garner had been on site since 5:00 a.m., CMS Parent Advocate Rodney Farley had been working for over a year to make the weekend a reality, and Steve Tew, Grant Strohbach, John Gould, Jared Johnson and Coach Vines from the Rollin' Razorbacks were there to run the clinics, along with Lori Buddenburg and her students from the Occupational Therapy Department at UCA. And, of course, there were the parents — those folks who got up early and drove from places like Jonesboro and Ola and Greenbrier and Bisco, who stood in the heat and cheered on their kids, wiping a tear here and there, giving hugs of encouragement and glowing at the successes and the self-esteem we saw grow in front of our very eyes.

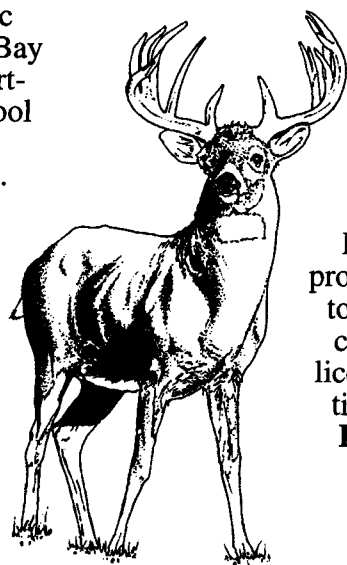
But, most of all, I was there because of guys like 6 year old Jake and 16 year old Nick, who were trying wheelchair sports for the first time, and wheelchair sports veterans like Tyler and Brandi, who shared their experiences with the novices. Super Spokes '98 was a great weekend. Anyone who was there would agree. I can't wait for next year!

Cheryl L. Vines

First Annual Disabled Sportsman Hunt

Plans have been made for the first Annual Disabled Sportsman Hunt sponsored by HealthSouth Rehabilitation Hospitals of Arkansas, Arkansas Therapeutic Recreation Society, Bay Volunteer Fire Department, Bay High School and **Buck Taylor** of Quickie Wheelchairs.

Tony LeQuieu of HealthSouth Rehab Hospital in Jonesboro has worked tirelessly to obtain supplies for this event. He has been successful in securing equipment, food and lodging for eight participants during the two weekend deer hunts scheduled



for November 13 and 20 at the Arkansas Disabled Sportsman Association Club in DesArc.

The November 13th hunt is already booked for eight hunters from Northeast Arkansas, but plans are underway with openings for the November 20th hunt. Participants need only to provide their transportation to and from DesArc and a current Arkansas hunting license. For more information, please contact **Tony LeQuieu** at HealthSouth Rehab Hospital, 870-932-0440, or ASCC Case Manager **Rose Trospen** in the Jonesboro office, 870-972-4923. ♪

Super Spokes '98



Super Spokes '98 Outstanding Female Athlete **Elizabeth Liberto** of Jonesboro and Outstanding Male Athlete **Tadd Crowe** of Prattsville are presented their trophies by Junior Rollin' Razorback Coach Doug Garner and ASCC VISTA Volunteer Steve Tew.

Spina Bifida Clinic

Continued from page 1

up appointments and sending follow-up mail reminders. As a result, attendance has increased. Appointments that have been cancelled can be rescheduled with another child in need.

Kim is also trying to coordinate appointments to assure that the children are set up for all of the services that they need (such as urodynamics, MRIs or x-rays). In SBC, the physiatrist, neurosurgeon, orthopedist, urologist, social worker, physical therapist and clinic nurse are available to see the children as needed. Kim and Becky are also available between clinics to answer questions and assist with obtaining services, but they recommend that families go to their Primary Care Physician (PCP) first. The PCP can then refer them to clinic. You can reach the SBC at (501) 320-1806.

Dr. Rick Boop, who served as the SBC Medical Director for the past year, resigned that position this summer and the hospital is actively recruiting for a new Medical Director. We appreciate Dr. Boop's many contributions to the clinic and our kids!

In addition to new staff, SBC has a new home in the Neuroscience Center for Excellence, which is located at the back of the hospital. The new clinic has much more space, more exam rooms and even has designated "spina bifida clinic" handicapped parking spaces right outside the door. Clinic is still held every Thursday.

Spina Bifida Clinic has come a long way in its 20 years of existence, now serving nearly 500 children and young adults with spinal cord disabilities. With Becky and Kim at the helm, we know it will continue to grow and expand! ♪

Defining Post-Polio Problems

By Frederick Maynard, M.D., Medical Director - Spinal Cord Injury
Professor of Physical Medicine & Rehabilitation, Case Western Reserve University, Cleveland, OH

In the broadest terms, there are many new health problems that persons with a previous history of polio may experience. These health problems can include those that are clearly unrelated to the history of polio, such as glaucoma or gall stones. For other health problems, such as coronary artery disease, it may be unclear whether there is a relationship to previous paralytic history because a sedentary lifestyle in polio survivors may cause an increased risk of developing coronary artery disease.

Systemic health problems, such as heart disease or diabetes, can impact and produce symptoms that overlap and mimic those of post-polio syndrome (fatigue, weakness and pain). This issue has led to confusion, misunderstanding and lack of consensus about what is meant by post-polio syndrome.

The term "late effects of polio" implies that new health problems are related to the original polio impairment, such as muscle weakness and related joint deformities. The term "post-polio syndrome" is a looser term which does not specify etiology, or

cause of symptoms. Post-polio syndrome commonly develops in people with polio residuals and mild symptoms are almost inevitable in people who are growing older with polio.

As a "syndrome," post-polio is a common symptom cluster — classically, pain, fatigue and new weakness — that is seen over and over again in post-polio people. The bottom line for having post-polio syndrome is new loss of function. Individuals with post-polio syndrome have new disability.

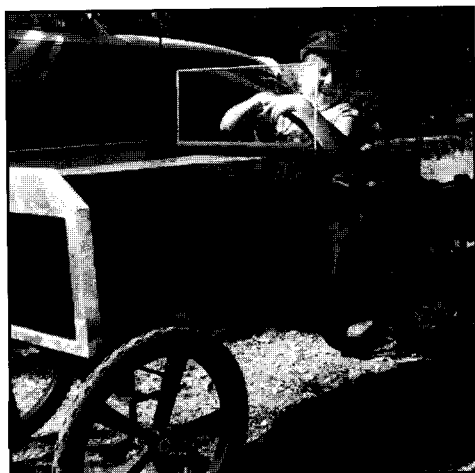
Post-polio muscular atrophy (PPMA) refers specifically to people who definitely had old polio weakness and are now having new weakness and atrophy from no other identifiable cause. PPMA is new or additional anterior horn cell disease that appears to be unexplainable. A slightly different concept has recently been proposed by the Institute of Medicine to describe new disabilities in people with long-standing disability. This has also been referred to as the development of secondary disability. For example, people with post-polio residuals, after

full recovery and rehabilitation, were left with a primary disabling condition. Other health problems may then cause the residuals (weakness, deformity) to become worse and result in additional new functional limitations.

Another new concept is the notion of "life course" of people with a history of polio. As people with paralytic polio histories become older, they can be expected to experience a level of functional decline when they are 70 or 80, similar to what non-polio people experience. However, their expected life course of slowly progressive weakness can be drastically accelerated by other life events, such as injury or the onset of other medical conditions, for example diabetes, heart disease and arthritis. &

Attention Polio Survivors

Dr. Mary Umlauf of the University of Alabama - Birmingham is doing a survey of sleep and bladder problems in individuals who had polio. If you are interested in participating, you may obtain a copy of the survey questionnaire by calling **Denise Roulhac** at 296-1792 or 1-800-459-1517.



April is very happy with her new truck designed by her ASCC Case Manager.

April's Really Truckin' Now!

April Bates (of Independence County) who turned eight years old last March and was born with spina bifida, has a new truck. This is the second vehicle designed and built by ASCC Case Manager **Charles Crowson** for April (see January 1994 issue of *Spinal Courier*). The first vehicle was a battery powered "Barbie Jeep" which April has outgrown. Now she has a much larger, gasoline powered truck patterned after a 1915 Ford pickup.

April's new truck has a ten horsepower, electric start motor, a five-speed manual transmission with reverse and a chain-driven rear end. The wheels are 20 inch E&J power chair rear wheels with 20 inch bicycle tires. The clutch and brake are operated from a single lever located at the left side of the seat. Charles designed the truck to travel a little faster than a lawn mower, but the speed can be increased as April gets older and accustomed to the truck. &

Management of Spasticity, Part II

Tom Kiser, M.D., ASCC Medical Director

As promised, in this edition of the Spinal Courier I will discuss how oral medication can help you manage your spasticity. I also will discuss the pertinent side effects and risks.

Side Effects and Benefits of Oral Medication in Managing Spasticity

- **Diazepam (Valium)** has been used for years to decrease the severity of spasticity. It works by decreasing the activity at the nerve synapse by increasing the effect of the inhibitory neurotransmitter, GABA. It is generally well tolerated except for making you drowsy. Other side effects are decreased motor coordination and impaired mental functioning. The potential for abuse and addiction are present and the street value of this medication make it a poor choice for spasticity management. Normal dosage is 10 milligrams three to four times a day. This medication has fallen out of favor with a lot of doctors who treat spasticity, because it is a controlled substance, addictive and other medications are better with less side effects.

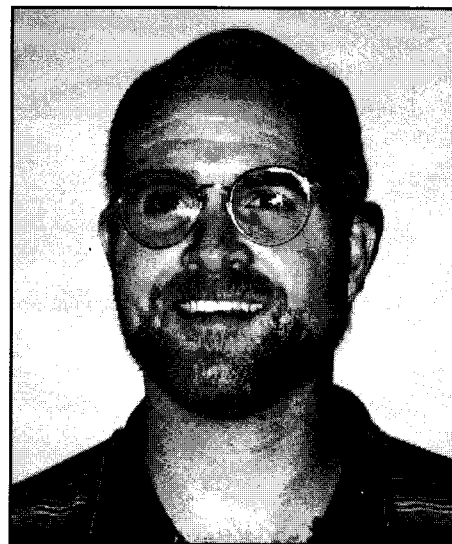
- **Baclofen (Lioresal)** is similar to the neurotransmitter, GABA, and directly inhibits the activity of the nerve synapse. It is the drug of choice in spasticity caused by a spinal cord injury since it is as effective as Valium but causes less drowsiness. It also may help with bladder management. The main side effect is drowsiness, but this wears off rapidly once you have been on baclofen for a short period of time. The main complication to be aware of is the risk of seizures and hallucinations which can occur if baclofen is stopped abruptly and not tapered down slowly. If you find yourself in the situation of not being able to refill your medication, slowly decrease

the dosage by about 5 to 10 milligrams a day until you get down to about 5 milligrams two times a day, then you can safely discontinue the medication. Normal dosage is 20 milligrams four times a day.

Your doctor should monitor your liver function tests routinely (approximately every six months initially and then yearly to ensure there is no adverse effect to your liver). Baclofen has been used safely for years by many patients with a spinal cord injury and is safe if used properly to manage spasticity.

- **Dantrolene (Dantrium)** reduces muscle action potentials by decreasing the release of calcium in your muscles, and decreases spasticity at the muscle level rather than at the nerve level. Its effect is more prominent in fast muscle fibers than slow muscle fibers and seems to have very little effect on the muscles of your heart or in your gut. It is mild to moderately sedative, and its main side effect is liver toxicity. Liver function tests should be monitored weekly when initially started, then monthly, and eventually yearly. If there is any sign of elevation of liver enzymes, dantrolene should be tapered down slowly and discontinued. The normal dosage is between 25 milligrams four times a day to 100 milligrams four times a day.

- **Tizanadine (Zanaflex)** facilitates the release of the inhibitory neurotransmitter, glycine, and prevents the release of excitatory neurotransmitters. It has been shown to be equivalent to baclofen in decreasing spasticity and may be better tolerated. Side effects include mild decrease in blood pressure, drowsiness, weakness and dry mouth — all



which usually resolve. The rare patient may have problems with hallucinations. This medication has been on the market for approximately two years but has been used widely in Europe for years. Because its site of action in the nervous system is different from baclofen, it can be used with baclofen to increase the effectiveness of both medications.

The judicious choice of medication based on its method of action, its side effect profile and its benefit to you can be quite helpful to you in managing spasticity. ✎

Free Legal Help

The American Bar Association (ABA) has coordinated volunteer lawyers nationwide to donate legal help to families with children with disabilities who are appealing the decision to eliminate their Supplemental Security Income (SSI) benefits as a result of the federal Welfare Reform Act of 1996 (see page 3 of the April 1997 *Spinal Courier*). In Arkansas over 7,000 children with disabilities underwent redetermination. Some did not meet the requirements and lost their benefits.

Appeals to continue benefits may be made, but require legal help. For more information, contact the ABA at (312) 988-6148.

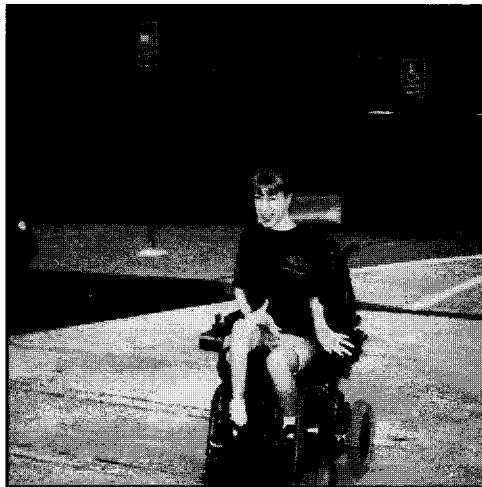
Advocating for Accessibility under the ADA – One Community's Story

By Sidney Case, Board President, River Valley Accessibility Council

The River Valley Accessibility Council (RVAC) is a grass roots group of concerned citizens who work with local businesses and institutions to ensure compliance with the Americans with Disabilities Act (ADA) in Pope County, Arkansas. We've come a long way in the short time that the Council has been active and have many successes to our credit. In the last year, alone, we have worked with the city of Russellville to develop a transition plan for making each of the city's facilities accessible. The RVAC was appointed as the Mayor's Advisory Committee for Disability Rights and serves as advisor for the City Planning Commission. In addition, the RVAC has helped over 15 businesses to increase compliance with ADA including the Pope County Courthouse and the national chains of Wal-Mart, Cracker Barrel, Wendy's and Burger King.

How have we been able to accomplish so much? How did we get started?

- **Anger:** To ignite anything you need fuel. In the case of the RVAC, it was anger. After spending six years out of state, my husband and I returned to Pope County only to find much of Arkansas still inaccessible and the hiring of persons with disabilities unheard of. I endured ramps from Hades, numerous interviews with the Brides of Frankenstein and access to the most basic services blocked at every turn. At this point I became not only angry, but I was furious and shocked. I said to myself, "I'm not going to take it anymore." I knew there must be others out there just like me who felt desperate for change. With the help of **Robert Griffin** of our local Spinal Cord Commission



Jessica Johnston, member of RVAC, in front of Peters Family Living, one the businesses that RVAC helped to come in compliance with ADA.

office and **Marilyn Bocksnick** of the Arkansas Council of the Blind, I contacted others with disabilities and invited them to a meeting to discuss the problems that we, the challenged community, face in the River Valley area.

- **Channeled Anger:** We had a good turn-out for the meeting and discussed our anger with city, county, and state officials, as well as with business owners and schools. After sharing horror stories of access and hiring practices, I asked the group, "What do you want to do about all of this?" We decided to work with businesses on accessibility issues and carry a big ADA stick rather than confront them directly.

- **Know Your Stuff:** Before we could put this plan into action we had to educate ourselves. We did this by reading and memorizing as much of the Department of Justice's ADA checklist as possible, by attending ADA training sessions for ourselves, by conducting role playing training sessions regarding accessibility problems and by pairing up more experi-

enced members with less experienced ones when making store inspections.

- **Site Inspections:** When we felt we were ready, we began site inspections. We first identified the areas that needed to be changed (ramps, parking spaces, etc.). Then we highlighted the ADA checklist which gave the regulations concerning the problem areas. At that point we asked for the owner/manager, introduced ourselves and gave them their copy of the problems and highlighted ADA checklist. We then explained how the problems prevented us from accessing their store. Before leaving, we gave them a letter from RVAC restating the problems we faced in their store and asked that they respond to our request within a reasonable time, usually 30 days.

- **Present Yourself:** Always use a businesslike manner when making inspections. Pick a time that would be slow for the type of business you are visiting — a restaurant owner is not likely to give you his full attention at noon time. Make an appointment, if necessary. Dress for success, as though you are going for a job interview. Always smile and present a business card introducing yourself and the group you represent. Expect some hostility: many managers feel you are there to take money out of their pockets. Always be courteous.

- **Emphasize the Positive:** Present the positive aspects of making the suggested changes to the manager. Reassure the business owner that most needed changes are often inexpensive. Emphasize the new customers

Continued on page 7 - see "Advocating for Accessibility under the ADA"

Advocating for Accessibility under the ADA

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who will be able to access their store when the changes are made. On the other hand, noncompliance forces potential customers to take their money elsewhere and threatens the risk of bad publicity and the cost of lawsuits, that the owner would most likely lose. The flip side is that good public relations with the disabled community shows that their business has a heart and is dedicated to customer service.

- **Legal Assistance:** If at all possible, hire an attorney! Go as a group to visit with him/her. Ask if the attorney will work with your group on a "pro bono" basis. Include in your agreement with your attorney, a request to send out letters on behalf of the group encouraging business to comply before a lawsuit might be filed. Have a general plan of action for dealing with inspections and fol-

low it. Document what you have done and where you intend to go. And by all means, if you need help ask for it. Call the Department of Justice ADA hotline if you are in doubt about anything.

- **Stay in Control:** Remember not to take it personally if some business owners become hostile. **Never lose your temper!** You represent your group in the community — if you lose control and leave the business owner angry, the reputation of your whole group is at stake. Let your attorney fight for you.

- **Praise Complying Businesses:** Lastly, once you have achieved your goal and a business is in compliance with the ADA, **visit and use** the facilities. Promote them as good community partners and friends of persons with disabilities. ♪

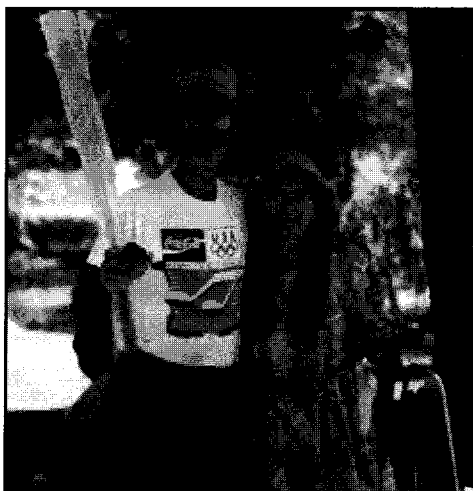
Wheels & Reels Fishing Derby

The tenth annual "Wheels and Reels" fishing derby, sponsored by the Spinal Cord Commission, was held on Saturday, May 16, 1998, at Bryan Lake on Lyon College Campus in Batesville. A large crowd of approximately 74 people participated — some having driven over 100 miles to attend.

Winners included: **Larry Matthews** from Yellville, men's division; **Charletta Hildersheim** from Yellville, women's division; and **Miles McShane** from Batesville, children's division. All winners received a rod and reel.

Part of the festivities included good food (fried chicken, potato salad, slaw and rolls) provided by donations from American Home-Patient, Wal-Mart, ConAgra and Citizens Bank — many thanks to these generous organizations!

Also, special thanks go out to Arkansas Game and Fish Commission for providing catfish to stock the pond and to Lyon College for the use of their lake. ♪



Batesville ASCC Case Manager Charles Crowson presents a rod and reel to the winner in the women's division, Charletta Hildersheim.

To Everything There is a Season . . .

A Guide for Caregivers of Farmers and Ranchers with Disabilities

- Video • Written Resource
- Leader's Guide • Overhead
- Transparency Masters

To Everything There is a Season . . . A Guide for Caregivers of Farmers and Ranchers with Disabilities is a self-contained resource package targeting rural caregivers. This resource can be used both by new and experienced caregivers to learn how to achieve and maintain a health balance in their own lives while positively impacting their families. It can also be used by rehabilitation professionals to help new caregivers in preparing for the stresses associated with caring for an individual with a disability or illness.

The resource package features an encouraging 45-minute videotape with advice from caregivers from across the country, experts in the field of caregiving and an assistive technology specialist. A Leader's Guide and overhead transparency masters equip you with everything you need for presenting to small groups or providing a workshop. Additionally, a written resource filled with color photos and a brochure are included, which provide advice on many aspects of caregiving.

For more information and to order this resource package, contact:

Breaking New Ground Resource Center
Purdue University
1146 ABE Building
West Lafayette, IN 47907-1146

1-800-825-4264
765-494-5088 (voice/TDD)
765-1356 (FAX) ♪

1998-99 Wheelchair Basketball Schedule

Rollin' Razorbacks

Nov. 14-15 At Nashville, TN
 Dec. 5-6 At Dallas, TX
 Dec. 12-13 Home
 Jan. 8-10 At Champaign, IL
 Jan. 23-24 Home
 Feb. 4-6 At Lexington, KY
 Feb. 27-28 Home
 Regionals TBA
 Final Four TBA

*All home games are played at
 Sylvan Hills High School in
 Sherwood, AR. For more infor-
 mation, call (501) 834-8513.*

Junior Rollin' Razorbacks

Nov. 21-22 Texas Regional
 at Dallas, TX
 Jan. 16-18 AR Regional at
 Hot Springs, AR
 Jan. 23-24 Mid-America
 Regional at
 Carbondale, IL
 Feb. 13-14 Lakeshore
 Invitational at
 Birmingham, AL
 Mar. 12-14 National Junior
 Tournament at
 Champaign, IL

*For additional information, call
 Doug Garner at (501) 525-4503.*



Fort Smith Shooting Stars

Nov. 7 At Tulsa, OK
 Dec. 5 At Muskogee, OK
 Dec. 12 At Memphis, TN
 Dec. 19 At Ft. Smith, AR
 Jan. 9 At Oklahoma City,
 OK
 Jan. 23 At Stillwater, OK

*For additional information,
 call Doug Moore at (501)
 474-0825. &*

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